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ABSTRACT

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Parents as Advocates for Handicapped Children:

Untapped Resources for Social Change in the 1980's

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ABSTRACT

Parent groups are the single most important factor behind the progress made in recent years in the rights of handicapped children. With the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975 the parent movement peaked. Since vocational opportunities and community living alternatives are inadequate institutionalization may have been delayed, not avoided, unless services for handicapped adults are expanded. The structural preconditions for a new parents' movement in the 1980's are present.

Using data from a county survey of 330 parents of developmentally disabled children (i.e., children with mental retardation, cerebral palsy, autism, or epilepsy), this paper examines parents' participation in and attitudes towards special interest groups and political activities. Findings indicate that parents are willing to participate in special interest groups and political activities to a much greater extent than they have actually done so. Organizational involvement is contingent upon the amount of stress experienced by the family, indicated by age of child, severity of the disability, and family income. Findings indicate parents represent a substantial potential force for social change in the 1980's.

INTRODUCTION

Parent groups are the single most important factor behind the progress made in recent years in the rights of handicapped children. Parents began organizing in the 1950's around concerns about conditions in institutions, human rights, alternatives to inpatient care, public school special education, and a range of community programs (Scheerenberger, 1976). They were the first to sponsor educational programs for their handicapped children. They organized to get the public school districts to accept their children as students. This parent movement culminated in the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975.

Educational concerns and community involvement are now the predominant ideology, as they were just over 100 years ago (Kanner, 1964). In the mid 1800's members of the medical profession (such as Seguin, Howe, and Wilbur) identified the "feebleminded" as victims of industrialization, unable to compete effectively, and a burden on those who could, unless they were given special training. The conditions of survival in industrial society require a degree of competency unnecessary in simpler cultures. Initially the medical profession fostered humanitarian concerns for the handicapped as victims of social problems due to their limited competencies. Experimental training schools were established with the goal that students would, upon leaving, better adapt to community life.

By the late 1800's the character of the experimental training schools, or asylums, began changing (Wolfensberger, 1975). A new ideology concerning the incurability of "feeblemindedness" fostered a decline in training efforts and the practice of warehousing began. Institutions became custodial in nature. Admission decisions were taken out of the hands of the medical profession and given to the court. These new policies stigmatized commit-

ment and made it increasingly difficult to return to the community once committed. Eugenics concerns for the handicapped as the cause of social problems, potentially capable of undermining the human race if not segregated, were fueled by developments in the social sciences (exemplified by the work of Darwin, Galton, Dugdale, Goddard, Binet). As large custodial institutions developed they were crowded, staff/patient ratios were low, training minimal, and conditions dehumanizing. Expansion was made economically feasible by utilizing the "borderline" handicapped to perform the menial labor required to keep the institutions functioning. A self-fulfilling prophecy was created. The handicapped were perceived as so marginal in terms of competence that they were placed outside the community almost entirely. Medical professionals recommended placement at birth; educational professionals excluded them from the public school system.

Then as now professionals were prompted to take major social action partly by their experience and partly by the dominant ideology of the times. Six major periods can be indentified, and charted in terms of the growth curve of institutional populations (Gray, 1977):

Treatment of the Mentally Retarded	Approximate Date Shift in Ideology Occurs	Ratio of Institutionalized per 1,000 Population
Family & community: special education and training	1874	.03
Establishment of custodial character of institutions	1900	.09
Eugenics campaign peaked	1925	.34
Advancement of medical technology	1950	.83
Parent movement	1969	1.00
Family & community: deinstitutionalization	1975	.78

By the late 1970's the parent movement had peaked. Parents' groups had taken on the role of monitoring existing educational, residential, and voca-

tional programs. Inflationary concerns and fiscal constraints in social service programs shifted the emhapsis from starting new programs to evaluating and optimizing existing programs.

Enabling children to remain at home through the provision of public education was a giant step forward. As children complete the public education process at age twenty-one, however, corresponding opportunities are necessary for handicapped adults in the community. Otherwise institutionalization may merely have been delayed, not avoided. It is likely that parents once again will have to take the initiative to create appropriate vocational and living alternatives in the community.

This paper examines parents' participation in and attitudes towards special interest groups and political activities. The extent to which a sizeable proportion of parents are organizationally inactive but willing to participate is utilized as an indicator of the potential for a new parent movement in the 1980's.

RESEARCH METHODS

Sampling Procedures

The population was defined as Lake County, Illinois, parents of developmentally disabled children ages 0-21 who received services in Lake County. For the purposes of this study, developmentally disabled is defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one or more of the foregoing, and whose handicap required more than 50 percent time in a special education program. Extensive correspondence and discussion with agencies at the State and local levels, as well as with individual facilities and parents contacted through the Illinois Governor's Advisory Council on Developmental Disabilities and local

organizations, resulted in the identification of 751 families. Because of adherence to regulations governing rights of privacy, mailings requesting parents to consent to participate in the study went out through the educational facilities serving Lake County: three special education school districts, a state residential facility, a federally funded early intervention program, and six private facilities. Due to the low percentage of consents received after the first mailing (37.7 percent) these educational facilities also conducted a follow-up mailing.

Data Collection Procedures

A computerized review of the literature and open-ended depth interviews with parents were used to construct a mail survey questionnaire. The questionnaire was pretested with 66 families of children attending three schools for the developmentally disabled in Evanston, Illinois. Following revisions based upon the pretest results, a 57-page mail survey questionnaire was developed for the Lake County population. Structured closed-ended questions were designed to provide data regarding:

--the manner in which parents first discovered that their child was developmentally disabled;

--the availability of extended family and community support networks for the parents and their children;

--the nature of the developmental disability, skill levels, and kinds of limits the children have;

--the manner in which parents successfully or unsuccessfully secure the community services needed by their developmentally disabled children;

--the current professional intervention encountered and its perceived value;

--parents' attitudes regarding the direct services currently used for their children;

--parental involvement in their children's educational programs and organizations concerned with developmental disabilities;

--parents' opinions about general policy directions for the provision of services for the developmentally disabled in their community; and

--long-term plans and objectives these parents have for their children.

Questionnaires were mailed out over the three-month period from mid-March to mid-June 1978 to the 458 families (61.0 percent) who finally consented to participate. Included with each questionnaire mailed was a return post card with the respondent's name and the statement, "I have mailed my completed questionnaire." Respondents were asked to mail the card separately, at the same time they mailed the completed questionnaire. Since the questionnaires themselves were filled in anonymously, the post cards were our only check on which consenting parents had, in fact, returned questionnaires. A follow-up letter with a second return post card was sent approximately one month after the questionnaire was mailed if we had not received a post card notifying us of its return before that time. These procedures resulted in the return of 330 completed questionnaires (43.9 percent of the families identified and contacted; 72.1 percent of the families who consented to participate).

Returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks.

Characteristics of the Research Setting

The study was conducted in Lake County, Illinois. The county is in close proximity to Northwestern University, which minimized travel time and expense. Lake County offers a wide range of services to developmentally

disabled persons. There is a major state-operated residential center for severely and profoundly retarded persons. There are other smaller residential programs operated by private non-profit groups. The county is known for its comprehensive programs of special education offered through the public school districts. There are several sheltered workshop facilities for developmentally disabled persons. Within the area alternative residential programs for developmentally disabled persons are beginning to be developed (e.g., community living facilities, foster home networks, group homes).

The area of Lake County was selected for the research population because: (1) it is geographically compact yet includes urban, suburban and rural populations; (2) it offers a wide variety of services for the developmentally disabled; (3) providers and consumers of developmentally disabled services have a history of cooperation with past efforts to secure related information; and (4) the county contains people of wide range of socioeconomic, ethnic and racial backgrounds.

Characteristics of Respondents

Although the questionnaires were mailed to both parents in two-parent families, almost all were completed by the children's mothers. Of these mothers, 20 percent had not completed high school, 33 percent were high school graduates, 31 percent had some college or special career training, and 16 percent were college graduates. In 1978 dollars, 33 percent had yearly family incomes before taxes of less than $15,000 (categorized as low income families for subgroup comparisons), 39 percent had between $15 - 25,000 (middle income), and 28 percent over $25,000 (high income families). The vast majority (86 percent) were currently married; that is, most children in the study were from two-parent homes. About half of the

mothers (48 percent) were employed outside the home, a group about equally divided between those holding full-time and part-time jobs. In terms of racial composition, 83 percent of the sample were white, 11 percent black, 3 percent Latino, and 3 percent Asian or American Indian. Of the children reported on in the questionnaires, 21 percent were identified by their parents as mildly retarded, 34 percent as moderately mentally retarded, 20 percent as severely and profoundly mentally retarded, 12 percent as having cerebral palsy, 4 percent as autistic, and 9 percent as having epilepsy.

Slightly more than one-third of parents (34.8 percent) have never attended meetings for parents of developmentally disabled children, other than parent-teacher conferences. Another one-third (35.4 percent) attend between one and four meetings a year. About one-eighth (12.0 percent) attended between four and twelve meetings a year and nearly one-fifth (17.9 percent) attend meetings one or more times per month. A near majority of parents (48.3 percent) are members of parents' groups or other organizations related to developmental disabilities.

FINDINGS

Involvement in Special Interest Groups

Many parents are willing to take an active role in their children's education because they realize they are the only persons who can provide continuity over the life cycle. They may hesitate to do so because they lack interpersonal experience in orgaizational involvement, feel overwhelmed by professional expertise, or have difficulty scheduling community activities due to family demands. As one respondent said:

> It is hard to find extra time. My husband and I work full-time. We rely a great deal on the printed information from the

school and organizations that relate to our child. We take full advantage of activities offered our child. But seldom participate ourselves.

Willingness or unwillingness to participate in parent groups raises the question of what barriers to participation exist. Out of a list of 7 reasons commonly given for nonattendance, the logistical problem of arranging for babysitters or transportation was reported as a barrier far more often than negative feelings about aspects of the meetings themselves (see Table 1).

TABLE 1 ABOUT HERE

For many parents, a natural process begins with the identification of their child as developmentally disabled. What starts as self-awareness grows into group social action. First comes the sharing of common concerns and information, with one-third of the parents having participated in group counseling and educational groups and another one-third who report a need for these group experiences (see items ranked #1-2, Table 2). Next comes organization to work for expanding and improving community services as well as for the rights and dignity of all developmentally disabled persons. Fewer parents have actively taken this next step with 16.2 percent having participated on a governing or advisory board and 12.4 percent having worked with a political advocacy group (see items ranked #3-4). There is a considerable untapped potential here with approximately one-third of the parents interested in taking this next step into community action (31.2 percent have not, but would like to, participate on a governing or advisory board, and 38.1 percent in a political advocacy group).

TABLE 2 ABOUT HERE

Organizational involvement is contingent upon the amount of stress experienced by the family. Three indicators of stress readily identifiable by organizational leaders, professionals or the knowledgeable public are age of the child, the type of disability, and the family's income category.

Age of child. The younger the child, the more likely parents were to have attended more than four meetings in the past year. Parents of pre-school-age children were most likely to have attended more than four meetings per year (46 percent) while parents of young adults (19 to 21 years old) were least likely (18 percent). It is the parents of younger children who are both more likely to have participated in group counseling and educational groups, and to be interested in doing so if they have not yet participated. Conversely, parents of older children are less likely to have participated and to plan to do so. On the other hand, age of child does not affect participation or interest in governing boards or political advocacy groups. This may represent a learning effect with older parents becoming more discouraged, or it may represent an optimism which younger parents will retain over the life cycle. Whether or not a new parent movement emerges in the 1980's will depend, at least in part, on whether the parents of younger children are reached and supported to extend their personal and informational needs into political work for social change.

Type of disability. The more severe the disability the more likely parents are to attend meetings often, and to maintain membership in groups or organizations. Parents of mildly retarded children are far more likely never to have attended meetings (51 percent) and not to have current membership in parent groups or organizations (80 percent). Similarly, the more

severe the disability, the more likely parents are to have participated or to want to participate in all four types of parent groups. The more severe the child's disability, the more likely parents are to realize their children will always require supervision.

Family income. Parents with higher family incomes are more likely to attend meetings more often, maintain current memberships and to become officers. Parents with higher family incomes are also more likely to have participated in all four types of parent groups. Parents with lower family incomes are more likely not to have participated, but do want to do so. Family income is not systematically related to unwillingness to participate. To the extent that organized groups can encourage the participation of lower income parents, for example by providing assistance with transportation and baby sitters, such parents have the potential for becoming involved to a much greater extent than they are at present.

At first, parents are usually preoccupied with their own children. Later, many come to the realization that programs die or will be cut back if they do not work for the rights and dignity of all developmentally disabled persons in their community, state, and whole nation. Parents' organizations have developed from sharing common concerns, to setting up their own facilities, and to becoming thoroughgoing advocates. Parents can become involved in parents' organizations in many ways--in the administration of programs, by starting new programs, and advocating for the legal rights of their child and handicapped persons in general.

Political Activities

Few of the parents in our sample have been involved in the typical political activities which influence local, state and national policies

concerning the developmentally disabled (see Table 3). More have taken individual action (27 percent have voted for candidates on the basis of rights for the developmentally disabled and 32 percent have written letters to government officials) than have made a public commitment (12 percent have attended political meetings and 9 percent have worked actively for a candidate). But the most striking finding is that a majority of parents are willing to undertake individual action and public commitment although they have not yet done so. This represents an untapped resource of considerable magnitude.

TABLE 3 ABOUT HERE

Age of child. In general, parents of older children were more likely to have engaged in individual and public political activities. Parents of younger children were more likely to be willing to engage in the individual types of political activities, that is, voting and writing letters. However, there was no association between age of child and parents' willingness to attend political meetings. And, it was the parents of older children who were more likely to be willing to work actively for a candidate who supports the rights of the developmentally disabled. As was the case for involvement in special interest groups, the emergence of a parent movement in the 1980's will depend in part on whether parents of younger children are encouraged and supported to generalize personal responses into public advocacy.

Type of disability. Parents of children with autism and with severe and profound retardation are the most likely to have engaged in political activities or to be willing to do so. Parents of children with cerebral palsy, epilepsy, and moderate mental retardation are intermediate. Parents of children with mild retardation report themselves as least as likely to do

these activities. But even amongst the most apathetic group, the parents of children with mild retardation, only one-quarter report that they are unlikely to vote or write letters and two-fifths, that they are unlikely to attend meetings or work for candidates. Clearly, the vast majority of parents whose lives have been affected by the birth of a developmentally disabled child, regardless of severity of the disability, are attitudinally predisposed to become much more involved in political activities.

Family income. The relationship between income and political activities is complex. Parents of high-income families are more likely to have engaged in the individual types of political activities and to have attended political meetings. They are, however, the least likely group to vote for a candidate solely in terms of the candidate's support for the rights of the developmentally disabled. In general, parents of lower-income families are more likely to be willing to engage in individual types of political activities and to attend political meetings although not having previously done so.

Parent Group Activities

Parents were more likely to know that parents' groups were involved with supporting their children's programs (see items 1-4, Table 4) than to be involved in starting new services (see items 5-7). Even in the most visible areas of parent group activities, self-help through the socialization of new parents and working as volunteers with the children, fully one-quarter of the parents did not know whether or not parent groups were involved. The level of ignorance rises to include almost one-half of the parents concerning knowledge about parent group efforts to start new services. Since all of the programs have newsletters this finding indicates that a means must be established to communicate information or to make it salient before parents will be mobilized into a new social movement in the 1980's. Parents

are more likely to become involved in the types of activities they know about (self-help, volunteer work with the children, and public relations).

TABLE 4 ABOUT HERE

In general, the older the child, the more severe the child's disability, and the higher the family income, the more likely parents were to know about parent group activities and to become involved themselves.

DISCUSSION

Having a child with a developmental disability provides a focus for parents to develop special interest groups. Our data indicate that parents are willing to participate in such special interest groups to a much greater extent than they have actually done so. These politically inactive but attitudinally supportive parents represent a substantial potential force for social change in the 1980's.

Barriers that block parents' participation are more likely to be due to logistical problems, such as babysitters or transportation, or lack of knowledge rather than due to unwillingness to meet with other parents. Parents of younger children are likely to attend more meetings than parents of older children. At this stage of the life cycle, they are more likely to be seeking for help for themselves through counseling or education than to be involved in groups advocating for the developmentally disabled in general. Correspondingly, they are more likely to engage in expressing political interests in individualistic ways, for example, voting or letter writing, than by working with others as a political group. Parents of older, adolescent and young adult children are less likely to attend meetings but more likely to have engaged in both individual and public activities.

There is an initial shock and period of adjustment for the parents following the identification of a child's developmental disability. With early intervention and special education programs available, the educational period of the child's life can be relatively normalized. In the absence of adequate opportunities and living alternatives another period of anxiety and anjustment emerges as the child approaches adulthood. The need for community services for developmentally disabled adults presents the social structural conditions for a parent movement in the 1980's if institutionalization of many of their children as adults is to be avoided. Whether a parent movement coalesces or not will depend in part upon whether the involvement of parents of younger children is channeled from personal concerns into group advocacy. As the respondents themselves realized, achieving this transition will require teaching parents to participate in a consistent fashion which can be maintained over their children's life cycle:

> I felt a great need for the support of such a group from birth to age 6. Now, I'm more comfortable. I feel that with the problems of adolescence, I will need the group again. I would like to see some sort of group living available in the community for a greater number of the retarded with meaningful work available. I feel that the parent groups must work toward this constantly.
>
> Most parent groups need a lot of involvement and time to accomplish anything significant. Most people have other commitments and responsibilities which also require time and interest. This conflict leads to inadequate participation.
>
> Too many of the parents I have met seem unwilling or unable to help the school or organization helping their child.

They seem to expect something for no effort. Other parents work exceedingly hard, so hard they exclude other social activities, Only a few seem able to achieve a middle ground as opposed to extremes.

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Table 1. Agreement with common explanations for nonattendance at parent meetings (rank ordered by frequency of agreement with explanations).

	Agree	Uncertain	Disagree	
1. It is difficult for me to arrange for babysitters or transportation.	32.8%	7.5	59.6	N = 305
2. It is a waste of time to go to parent meetings because they never seem to talk about things related to my child.	17.7%	15.4	66.9	N = 305
3. It is a waste of time to go to parent meetings because the real decisions are made elsewhere.	15.3%	17.2	67.5	N = 308
4. I do not feel comfortable with the kind of people who attend.	12.1%	14.3	73.6	N = 307
5. I do not like to go to parent meetings when they are held in a public place, such as a community center or library.	8.7%	16.8	74.5	N = 309
6. The people who run the parent meetings do not seem to care about me.	8.6%	17.1	74.4	N = 304
7. I do not like to go to parent meetings when they are held in my developmentally disabled child's school.	6.8%	12.3	80.9	N = 310

Table 2. Involvement in and attitudes towards four types of parent groups (rank ordered by frequency of participation).

	Have Participated	Haven't—would like to	Haven't—don't plan to	
1. Group counseling (where parents meet to discuss their attitudes and feelings toward their developmentally disabled child).	38.8%	30.9	30.3	N = 317
2. Educational group (dealing with techniques of child rearing and development as related to developmental disabilities).	32.1%	39.1	28.8	N = 312
3. Governing or advisory board (dealing with the administration of an organization or facility for the developmentally disabled).	16.2%	31.2	52.6	N = 308
4. Political advocacy group (working to expand options and services for the developmentally disabled).	12.4%	38.1	49.5	N = 307

Table 3. Involvement in and attitudes towards political activities.

	Have Done	Willing to do	Unlikely to do	
1. Vote for a candidate you thought would work for the rights of the developmentally disabled regardless of the candidate's party or position on other issues.	27.3%	55.6	17.0	N = 311
2. Write letters to government officials to influence legislation for the developmentally disabled.	31.9%	53.0	15.0	N = 313
3. Attend political meetings to find out candidates' positions on the rights of the developmentally disabled.	12.2%	54.0	33.8	N = 311
4. Work actively for a candidate who supports the rights of the developmentally disabled (for example, passing out leaflets, displaying a campaign poster).	9.1%	50.8	40.1	N = 309

Table 4. Awareness about the involvement of parent groups in children's programs contrasted with personal involvement (rank ordered by known parent group involvement).

	Parent Group Is Involved (N = 308)			I Am or Have Been Involved (N = 314)
	Yes	No	Don't Know	% Yes
1. Socialization of new parents (for example, sharing your own experiences).	51.9%	21.5	26.9	37.6%
2. Working with the children in the program (for example, volunteer, room mother, teacher aide).	42.5%	30.5	26.9	28.0%
3. Outreach to the community (for example, lobbying, fundraising, obtaining media coverage, presenting educational programs about developmental disabilities).	42.5%	22.7	34.7	26.8%
4. In-house activities (for example, office work, building or classroom maintenance, working on newsletter).	30.5%	28.2	41.9	11.1%
5. Laying the foundation for new services or programs (for example, organizing a new kind of parent group, babysitting service, a recreational program).	28.9%	24.6	46.7	15.3%
6. Supporting a network of services for the developmentally disabled (for example, visiting other facilities, sponsoring joint meetings, building a coalition, acting as a liaison).	27.2%	25.6	47.1	17.5%
7. Laying the foundation for new facilities (for example, creating a new school, sheltered workshop, or living facility).	25.6%	29.2	45.1	11.5%